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ABSTRACT

Projects and research studies, often involving minority or low income students, developed by two medical specialists, focused on health attitudes and behaviors of elementary school students. A 2-year study of the impact of allowing students to initiate their own health care, with the aid of school nurse practitioners, identified distinct characteristics of frequent utilizers of school health care. These findings reinforced those from later studies on children's decision making processes in self initiated health care. Several curricula were developed to teach children to identify symptoms and to initiate appropriate responses to several health problems: (1) Actions for Health, a four-unit supplement to traditional health programs; (2) Circle of Care program, which presents teachers with insights into the family background of their students; and (3) a teaching unit for Egyptian schools based on the Actions for Health and Circle of Care programs. The major lesson learned from the studies is that, if one talks and listens to children, it is apparent that most are quite rational and more competent to deal with health matters than adults choose to believe. (FG)

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Teaching Children Self-Care:
A Counter-Cultural Proposal

Presented at the "Learning for Life"
Conference on the Future of Health Education
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Teaching Children Self-Care:

A Counter-Cultural Proposal

Good titles are, at the same time, descriptive and provocative. Hopefully at the end of this presentation, you will feel that this title meets both criteria. However, to provide the means to make that judgment, it will be necessary for us to chronicle our research with children over the past 12 years.

The Beginnings

As with much research, this story began with clinical observations. These were made by Mary Ann Lewis in 1965, while serving as a pediatric nursing specialist in a children and youth project in Kansas City, Mo. Her office was situated adjacent to a public elementary school, which served children from many of the families she had gotten to know as she made her rounds or home visits to the community. One day, one of the students, a member of a family she had come to know well in the course of providing services, dropped into her office after school "just to talk." This conversation about health-related topics was repeated with other students. Before long, she had acquired a panel of patients who came on their own to see her about a variety of things, including health-related matters. It seemed only appropriate to formalize this arrangement, so she began making appointments for her clients.

At this time, Dr. Charles E. Lewis was involved in a randomized control trial of nurses providing care to patients with chronic disease. His major concern was improving the illness behavior of adults. Mary

Ann Lewis had the impression that her patients, those children who had assumed responsibility for making appointments and looking after their own health, talked about health in different terms. She asked if anything were known about the origin of the health-related beliefs and behaviors of adults; an answer to that question was deferred for five years.

In 1970, we moved to Los Angeles. At this time a search of the literature revealed only a handful of studies of children's beliefs and behaviors related to health and illness. That year, we found a site for a project we called "Child-Initiated Care" -- the University Elementary School (UES) at UCLA. In 1971, we received a grant from the National Center for Health Services Research to examine the health-related beliefs and behaviors of children, and the impact of allowing children to initiate their own care from a school nurse practitioner. Mary Ann Lewis was one of three nurse practitioners providing full-time nursing services during the year of the study. The system worked as follows. Children who felt they needed to see the nurse took a "care-card" from boxes distributed throughout the school. The care-card was perforated into three parts serving as part of the communication system for child, teacher and nurse. Children wrote their names on the top part and left it with one of the teachers before proceeding directly to the nurse's office. They were examined, a history was taken, they were given the results -- the data base -- and asked to participate in the decision-making processes related to their treatment and disposition. Information for the teacher was written on the second perforated portion of the card and returned to the teacher by the student. The third

protion was part of the nurses' records. Students were interviewed before the initiation of this system, and at yearly intervals.

The results of the study can be summarized as follows:

1) By the age of 7, children exhibited patterns of utilization similar to those recorded for adults. That is, 20-25 percent of the children never came to the nurse's office during a 2-year period. We know they sustained minor injuries on the playground, but these children did not seek attention. On the other hand, 10-15 percent of the students made over 50 percent of all of the visits. These students were well -- they did not include those children enrolled in the school who had major chronic illnesses. They were children who had a higher perceived vulnerability, and believed that the benefits of care were greater than their classmates. In examining the medical care use of these children and their families, we found that the mothers of high users more often visited physicians. The rate of being taken to the doctor was significantly higher for "worried well" youngsters than for their colleagues.

Over a period of two years, it was possible to teach these children the fundamentals of decision-making on a one-to-one basis. After several visits for headaches that began during certain times of the day, students would come in and say, "Mrs. Lewis, I have another math headache." While children were able to more properly attribute the source of their discomfort, they continued to visit the school nurse. The intervention did not alter their behaviors. There were changes in children's beliefs, but not in their patterns of care-seeking.

In discussions with the teachers in the school, we found that children who were high users were reasonably well known to them. The

teachers perceived the high users to be children who had problems making decisions related to many aspects of school activities. Based upon this input, and with the conviction that a useful intervention must not be delivered only in the nurse's or physician's office, in 1975 we began the development of a curriculum entitled Actions for Health. We shall discuss it in considerably more detail later.

Children's Decision-Making

While the the research project terminated in 1974, the system remained in place. In 1976, school officials called us for a consultation. They had been asked by the Department of Pediatrics to participate in a trial of an influenza vaccine. The opportunity to examine a fundamental question was obvious. Why not let the children participate as real decision-makers with regard to the vaccine trial? We visited the classrooms of those grades eligible for the trial and explained to students the nature of the request, i.e. a new vaccine had been developed for influenza, and the doctors had asked if they would be willing to test its effectiveness. We stopped with that and asked for questions. The resultant discussions were, in a collective sense, the equivalent of a review by the Human Subjects committee. The students spontaneously asked all of the right questions. Why were they selected? What would they get out of it (i.e. the benefits)? What were the risks? What would it involve? All of their questions were answered.

The children were informed that school officials had agreed to let them make the first decision with regard to their participation. They would be allowed to decide if they would like to share this decision with their parents (who would have to provide the ultimate consent). If they said "No," they would not be considered further. Table 1

illustrates the responses obtained. You will note that a high proportion of children (more than we expected) agreed to share the decision-making with their parents. They said they would like to participate, or were uncertain. As a matter of fact, as demonstrated in the following table, Table 2, the children were far more positive in their response than were their parents. When one examined the pattern of response in terms of volunteering for the trial, as a function of their rate of use of health services at the school, it was apparent that high utilizers more frequently volunteered for the trial than those who were non-users or had lower rates of visiting the nurse.

Because of the unique nature of the setting where the first child-initiated care was conducted, we sought to replicate this study in the "real world." In 1976, we found a very real world -- a public school system that agreed to allow us to repeat the study in four schools serving primarily children from disadvantaged families. Table 3 describes the population of these four schools. You will note that in two of the schools, no change was made in the health-care system. One of these schools was served by a nurse and the other by a school nurse practitioner. In the two experimental schools, the care-card system was installed, and in one of these -- in the second year -- children were involved in the decision-making processes related to their care.

The results of this experiment were very similar to those of the initial study. Rates of use were much higher amongst black or white disadvantaged children. Children from Mexican-American families had a rate of visiting the nurse that was approximately 60 percent of the other groups'. Eliminating barriers to visiting the school nurse

resulted in increased utilization. However there was less of an increase among Hispanic students. We also observed an increase in the rate of pretending to be ill among all children in the experimental schools as children discovered the functional use of the sick role. There were some striking differences in health beliefs by ethnic groups.

In addition to this replication of Child-Initiated Care, we have completed studies of health-related beliefs of school children in urban areas of Switzerland, Egypt and Yugoslavia. While there are some significant differences, there are more similarities in children's beliefs than some might expect.

In 1979, because of our experience in developing the decision-making-based curriculum, Actions for Health, members of the Center for Interdisciplinary Research in Immunologic Disease (CIRID) at UCLA asked if we would be interested in developing a program for children with asthma. Once again, in collaboration with Ann de la Sota, and a pediatric allergist partner, Dr. Gary Rachelefsky, we set out to develop a series of lessons that would have as their primary objective the transfer of management of asthma from the parent to the child. In other words, the lessons were to foster maximum self-management of the patients' disorder by the patients themselves. ACT for Kids, or Asthma Care Training for Kids, consists of five lessons taught separately to parents and children for the first 45 minutes of each hour, with a period of sharing at the end of each session.

As indicated in Table 4, the lessons focus on 1) identification of symptoms and signs of asthma, 2) the sources of irritants and allergens in the environment that need to be eliminated or minimized, 3) medication-taking -- understanding what drugs to take, when and for how

long, 4) decision-making -- once again as an overlay, and 5) balanced living.

We are now completing a randomized control trial of ACT for Kids in Los Angeles that has involved 50 children in each control and experimental group. Our one-year follow-up period for the last treatment group will end in the fall of 1982. In Act for Kids, we found that learning and communication between parents and children was facilitated by the use of a paradigm familiar to all -- the signs and symbols associated with traffic safety. Medicines and allergens are coded green, yellow or red, depending upon their use/severity -- green medicines to keep going, to prevent asthma; yellow for symptoms that cause you to slow down; red medicines to stop the severe episodes/symptoms.

Body maps are used along with symptom stickers, providing an active means for children and parents to identify those aspects of the problem which are unique to them, versus those similarities shared with others in the group. The group process with parents facilitates the adoption of a new norm by all parents; that is, allowing children access to medications in order to properly control their asthma.

In 1981, we were awarded a grant by a foundation to develop a curriculum for Mexican-American children, who had recently immigrated to the United States. We began this curriculum assuming that we would provide instruction in home-nursing skills. We saw this as the American equivalent of David Morley's Child-to-Child program. As some of you may know, this is a program which has met with considerable success throughout the developing world. It is predicated on the assumption that the one resource that is always available to care for a young child

is an older sibling. Therefore, older children are taught a variety of care-taking skills.

Our early work demonstrated that there was considerable variation in the types of family roles and responsibilities expected of these children. We have subsequently developed a series of lessons that are being taught in bilingual classes. They are concerned with safety and family interdependence. We have chosen to call the latter lessons "The Tree of Shoes." It focuses on the functions within the family that each member is responsible for, as well as the extent to which the family as a unit is dependent upon the efforts of all of its members. To develop a Circle of Care (I care for my family and my family cares for me) required us to conduct some basic ethnographic studies in the Mexican-American community in order to have some sense of the values and structure of these families so that our lessons would not be counter-cultural."

Our more recent activities have involved developing a curriculum for children with epilepsy, similar to that of the program for asthmatic children, and a collaborative project with the Ministries of Health and Education in Egypt, where we have begun the development of a supplementary health education curriculum which focuses on the active learning of basic skills associated with personal hygiene and sanitation.

Lessons Learned

From these studies, several messages have become clear to us:

1) Children are under-valued by adults. That is, adults perceive children to be far less competent than they really are.

2) Health as a concept is not salient for children -- just as it is not for adults.

3) While many adults are concerned with children's health, they become even more concerned if children become unchildlike and begin to look after themselves. No one is concerned as long as children are lectured to about what they should or should not do. However, when they become active participants in their own care, or are encouraged to put that advice into action, many adults are extremely discomforted.

The School as Setting for Health Education

We should like to describe three health education programs we have developed in the school setting. Our experiences with these provide support for the counter-cultural nature of the endeavor we are describing.

Actions for Health was designed as a supplement to balance the more traditional content emphasis of other health programs. It consists of four units. The first two are general process units, followed by two health application units. The first, Decision-Making, teaches the basic processes of making decisions, including the types, as well as the steps of decision-making. Decision-making is taught through active participation in familiar situations before being applied to health decisions in later units. The second unit, Self-Reliance, introduces strategies to increase children's independence and abilities to distinguish between circumstances when it is appropriate to ask for help. It emphasizes the process of self-reliant decision-making as the key to improving children's self-care behaviors.

Body Cues increases children's awareness of symptoms as cues to action for the 11 most common childhood illnesses and injuries and helps children make appropriate self-care decisions. Balanced Living rounds out the program with the application of decision-making to all areas of daily living. The program is presented in the form of a teacher-resource book and includes 25 core lessons, 22 optional lessons, and 68 black-line masters for worksheets, forms and game parts. Each unit provides detailed lesson plans for active learning. Parents can be involved by the use of a sample letter sent home at the beginning of each unit and by participation in suggested home extension activities related to each lesson.

Actions for Health was designed with the following principles in mind:

1) No additional, expensive materials should be required for teaching.
2) The lessons are teacher-ready. That is, no inservice training programs are necessary.
3) The two foundation units are designed as generalized-overlay units to be integrated in a variety of other content or subject areas.

From 1978 to 1980, we conducted a randomized control trial of Actions for Health. Seven sites across the country -- including rural Maine; Pittsburgh, Pa.; Gary, Ind.; suburban Chicago; rural Arizona, and smalltown California -- participated. After approval from boards of education, schools were randomly assigned to experimental or control groups; teachers in the experimental schools were provided copies of

Actions for Health and "requested" (expected) to use the material. Local field coordinators at each site collected pre- and post-test data, assessed teacher effort, and collected data on teacher satisfaction. The study involved more than 90 second-grade classes and 90 fifth-grade classes -- more than 4,000 children in all. The loss in terms of student attrition was less than 10 percent. The impact of curriculum in this particular phase of the testing was assessed through pre-test/post measures primarily of students' knowledge and the application of knowledge from curriculum materials. A repeated measures analysis of variance was used to assess its impact and to adjust for differences in scores on the basis of districts and so forth.

Teacher satisfaction varied considerably with the lessons. Most teachers enjoyed and were pleased with the two core sets of modules, Decision-Making and Self-Reliance. Only about half were pleased or satisfied with the Balanced Living/General Health content area. Body Cues, or the section concerned with teaching children self-care, was the least appreciated of all -- only 35 percent of teachers found it probably of value, and only a minority of them taught it with enthusiasm.

As we examined the nature of the "treatment," we found it necessary to separate teachers in the experimental group into three sub-groups: those who taught the lessons with enthusiasm, those who were assessed by coordinators as doing a reasonable job (neither negative nor enthusiastic in their approach), and a third group who were definitely negative or hostile in terms of the effort applied in teaching. All of these teachers taught the curriculum; they simply taught it with differing degrees of effort.

As many of you might suspect, the analyses show that compared to the control schools, a significant impact was found only among those teachers who taught the curriculum and were positive in their approach, i.e. who viewed it with enthusiasm. There were slight, but non-significant, gains among unenthusiastic teachers in the experimental group. Thus, to quote McLuhan, once again, the medium is the message. Teachers who found some of the content offensive or contrary to their views as to what children should be expected/allowed to do presented the material, but there was no evidence in terms of pre- and post-test changes to document its impact.

The Circle of Care program, designed to teach a variety of skills to Mexican-American children, also has presented us a lesson upon the extent to which teachers' attitudes and values enormously influence the intent of the lessons. As mentioned previously, we have had two anthropology doctoral students living in the community where this curriculum is being taught. They have observed and interviewed teachers in the target school, as well as families. Their data demonstrate clearly the extent to which this curriculum, which examines the cultural and geneological backgrounds of the students, presents teachers with information that conflicts with some of their prior stereotypes about the families/students in their classes. Many teachers have viewed this with enthusiasm and have appreciated the insight provided by the lessons and the homework that comes back. Other teachers seem discomforted. As one put it, "It's the child that is important; the family background isn't that important." Circle of Care profits from what we learned from

Actions for Health, i.e. to be attuned to the importance of collecting data, not only from the students and the families, but also from the teachers.

Our most recent experience has occurred at the greatest distance. The study of health-related beliefs and behaviors in Egyptian school children led to the development of a supplemental curriculum that focuses on the teaching of skills related to hygiene and sanitation to elementary school children. The current curriculum in Egyptian elementary schools is taught within the science curriculum and is full of accurate information but relatively devoid of active learning activities. This project involves a third group -- sociologists from the American University in Cairo, who have conducted interviews with teachers before and after the development of the lessons. Our Egyptian colleagues/counterparts have been to California, observed many of the activities we have described and "Egyptianized" (their term) many of the lessons/materials developed for Actions for Health and Circle of Care.

As we look forward to the testing of the impact of the curriculum in 1982-83, the sociologists will be heavily involved in its evaluation. The principal investigator, Dr. Alia Ayoub from the Ministry of Health, has come to share our belief that the principal target of this intervention is not the students, but teacher-training institutes in Egypt.

On the basis of this travelogue, let us restate our conclusions:

1) Children learn via social learning a great deal about illness and something about health before they reach the formal (Piagetian) operational stage of cognitive development. They learn much about the use of the sick role.

In school, they interact with another constellation of adults, who have a distinct set of values with regard to what health is, and what is appropriate for children, with regard to their own health maintenance.

2) Throughout the world, we have found little evidence that children are interested in health, thus confirming the original observations of Anna Freud. Younger children define health in a very broad way, such as being happy or being able to play. Unfortunately, as they grow older, their definition takes on a more limited or medical perspective, i.e. concerned with physical disabilities and symptomatology.

3) The major lesson we have learned is that if one talks to children and, more importantly, listens to them, it is apparent that most are quite rational and more competent than adults choose to believe.

However:

4) Children basically are "prisoners" or pawns of an adult society; they are passive participants in activities for which they will be expected to assume responsibility, without more formal training or practice, at some magical age.

Children tend to be talked to by parents and relatively ignored by health professionals (except nurses). They have a rather limited scope of decision-making (and they are aware of it), and efforts to enlarge that scope must consider the families' values and reciprocal role functions within the social units.

Finally, teachers, like all adults, have strong views and values about children's roles in society. If one is to consider the teaching of self-care to children, and do it in more than a didactic or intellectual fashion, one must be aware of the social impact of this approach on adults within the system. Perhaps as with prevention in childhood, we must intervene early in the teacher socialization process and involve teachers in active learning about children's health practices.

TABLE 1: CHILDREN INVOLVED IN THE INFORMED CONSENT PROCESS

	Boys	Girls	Total	Percent
At "risk"	93	120	213	100
Decisions				
Yes	18	26	44	20.7
?	24	47	71	33.3
No	51	47	98	46.0
Letter Sent Home	42	73	115	54.0

TABLE 2: PATTERNS OF USE (1975-76) OF THOSE INVOLVED IN INFORMED CONSENT STUDY

	Number	Patterns of Use (%)		
		No. Visits	1-6 Visits	High Users
All Children at UES	376	30%	52%	18%
At Risk-Exposed to Informed Consent	213	26	51	23
Volunteers (Yes--?)	115	15	53	32
Receiving Vaccine	15	33	27	40

TABLE 3: Characteristics of Schools/Children Involved 1976-78 - Pomona, Calif.

	Schools				
	A	B	C	D	Total
Number Continuously Enrolled	242	262	375	415	1296
Ethnic Distribution*					
White (%)	27	39	14	37	29
Black (%)	50	4	41	15	28
Mexican-American (%)	18	56	44	35	38
Percent Families on AFDC	30	46	34	42	38
Percent Children with Chronic Illness	5.3	2.3	2.5	5.7	4.3
Type Intervention	NP + Care Cards	NP + Care Cards	Control	Control NP**	

* The others are Asian.
** Nurse Practitioner.

TABLE 4: CLASS SESSIONS IN ACT FOR KIDS

1. What asthma is and how it affects my body --

   WARNING SIGNALS

2. Why I have asthma and what sets if off --

   ROAD BLOCKS

3. What to do and when to do it --

   TUNE-UPS

4. How to decide --

   ROAD MAPS

5. How to balance my wants and needs --

   MAINTENANCE AND SERVICE